



# NETWORK NEWS

News from the Utah Birth Defect Network

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## An Etiologic Classification of Birth Defects in Utah

Knowledge about the cause of birth defects in humans is extremely important in order to develop strategies for prevention. With the recent advances in identifying developmental genes and the discovery that folic acid prevents neural tube defects, the potential for future prevention strategies are even more realistic. Few investigations on the epidemiology of birth defects have systematically examined the precise description of birth defects in a well defined population.

With the collaboration of the Utah Department of Health, the University of Utah, and the Centers for Disease Control and Prevention, the Utah Birth Defect Network (UBDN) monitors all structural birth defects occurring in the state. The UBDN has been actively ascertaining birth defects since 1994, expanding to include all structural major malformations in 1999, with the exception of isolated clubfoot, hip dysplasia, and ventricular septal defects. These latter defects are not monitored because of the difficulty in definition of diagnosis.

We performed a study from the cases included in the UBDN examining the cause of birth defects in Utah for those babies born between 1999-2003. Using the algorithm (table below) cases are classified as either isolated or multiple and then further classified if etiology is known (chromosomal, single gene, or teratogen). Isolated malformations classified as such require one major birth defect (or one major affected organ system) to be present. Whereas, multiple malformation refers to two or more major birth defects, usually involving different organ systems or that have a known cause. Known teratogens can either be a medication (such as valproate) or maternal states (such as insulin dependent diabetes). This classification was only used if the exposure was a well-established risk. This etiologic

classification scheme, unique to the UBDN, is important for analysis so that analytical groups are similar.

The overwhelming majority of congenital malformations (71.5%) are classified as isolated. Isolated malformations generally have no known cause and are thought to be multifactorial. Multifactorial refers to birth defects that are thought to be due to a combination of genetic and environmental factors. Only 17% of birth defects were due to a known cause (single gene, chromosomal or teratogen). Previous studies have suggested that environmental factors are responsible for less than 5% of birth defects. However, our study would suggest that environmental causes (teratogens) only account for an even smaller proportion (< 1.0%) of birth defects in Utah, the majority of these being due to maternal diabetes.

John C. Carey, Marcia Feldkamp

This work was presented at the 25<sup>th</sup> annual David W. Smith Workshop on *Malformations and Morphogenesis* at Snowbird, Utah in August 2004.

Isolated Malformations	%
Isolated	71.5
Multiple Malformations	%
Chromosomal	14.7
Single Gene	2.5
Teratogen	0.4
Majors with and without Minors	10.1
Twinning	0.9

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### Utah Birth Defect Network

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## Update on UBDN Surveillance

As of January 2005, I became the Surveillance Coordinator. I received my B.S. from Weber State University majoring in Health Information Management. I will continue to pursue a Masters of Science in Public Health at the University of Utah. Because I moved to a new position, an additional data abstractor was needed. Kimra Castleton joined the Surveillance Team as a Data Abstractor in February 2005.

The Surveillance Team has been working hard to complete all 2004 cases. Our goal is to complete each case within 4 months of receiving the first report. The Surveillance

Team has reviewed 1,454 potential cases, processed 841 cases and met the 4 month goal with each case, taking an average of 3.6 months to process. Achieving this goal would not have been possible without the help of each of our contacts at hospitals, clinics, and other facilities. We appreciate your cooperation and prompt responses to our requests.

What do we do with all of the information that we collect?

The UBDN submitted several indicators to the Utah Indicator Based Information System for Public Health (IBIS). These indicators

include: Down syndrome; Birth Defect Related Infant Mortality; Overall Birth Defects; Neural Tube Defects; Heart Defects; Oral Facial Clefts; and Folic Acid. The IBIS system allows public users to obtain information for analysis and reporting. IBIS can be accessed at [www.ibis.health.utah.gov](http://www.ibis.health.utah.gov)

The UBDN also submits annual data to "Birth Defects Research Part A: Clinical And Molecular Teratology", a national Journal that publishes birth defect statistics.

Miland Palmer, B.S., RHIT

## Update from the Utah Center for Birth Defects Research

The Utah Center for Birth Defects Research and Prevention is a research project within the Utah Birth Defect Network. The Utah Center is one of ten Center's nationally to participate in the National Birth Defects Prevention Study (NBDPS), a case-control study investigating risk factors for birth defects. The Utah Center began inviting women to participate in the

interviewing phase of the study December 2003. The interview covers a wide range of topics about the mother and father including demographic information, family history of birth defects and environmental exposures.

To date, the Utah Center has completed over 700 interviews of both case and control mothers. Each Center also collects cheek cell sam-

ples on all participants to obtain genetic information. Utah mothers have been very willing to participate in this study. This information may lead to new prevention strategies for birth defects. For more information about the NBDPS, contact Amy Nance at [aenance@utah.gov](mailto:aenance@utah.gov) or 1-866-871-1586.

## Dr. Lorenzo Botto joins the Utah Birth Defect Network

I came to Utah from a decade of work at the birth defects center at CDC in Atlanta. There, much of my work focused on ways to reduce the risk for birth defects and promote the health of people born with these conditions. My goal in Utah is to help grow an integrated perspective that focuses, rather than on the conditions per se, on people with birth defects and genetic conditions -- their health, their needs, their concerns on causation, their

hopes for the future.

I believe that at every step of the way, we need good data (accurate, timely, and ongoing). We need data that addresses both the group with the person, epidemiology and the clinic. And we need these data to get to those who need it, quickly and in a form that is helpful.

That is why I am delighted about the opportunity to come to Utah, where the Utah Birth Defects Network and

the Department of Pediatrics, together with their partners, are doing such a superb job, and where already in these few months I have seen a level of skill, quality, and collaboration that is difficult to come by anywhere. I look forward to meeting and working with you in the times ahead.

Lorenzo Botto, M.D.  
Medical Epidemiologist

# West Nile Virus in Pregnancy



## Screening During Pregnancy

No specific treatment for West Nile Virus (WNV) infection exists, and the consequences of WNV infection during pregnancy have not been well defined. For these reasons, screening of asymptomatic women for WNV infection is not recommended.

## Diagnosis of West Nile Virus Infection During Pregnancy

Pregnant women who have meningitis, encephalitis, acute flaccid paralysis, or unexplained fever in an area of ongoing WNV transmission should have serum (and CSF, if clinically indicated) tested for antibody to WNV. The preferred serologic test of serum and CSF is West Nile Virus IgG and IgM by MAC-Elisa. Testing is available in Utah through ARUP and the Utah Public Health laboratory (only test performed is IgM at this lab). If serologic or other laboratory test indicate recent infection with WNV, these infections should be reported to the Utah Department of Health, and the women should be followed to determine the outcomes of their pregnancies. Only 20% of people infected with WNV have symptoms.

## Evaluation of the Fetus in Pregnant Women with WNV Infection

If WNV illness is diagnosed during pregnancy, a detailed ultrasound examination of the fetus to evaluate for structural abnormalities should be considered no sooner than 2-4

weeks after onset of WNV illness in the mother, unless an earlier examination is otherwise indicated. While adverse effects on the fetus are not well characterized, there have been reports of central nervous system complications. Referral to a specialized perinatal center for a detailed ultrasound examination should be considered. Amniotic fluid, chorionic villi, or fetal serum can be tested for evidence of WNV infection. In case of miscarriage or stillbirth, testing of all products of conception (e.g., placenta and umbilical cord) for evidence of WNV infection is advised to document the effects of WNV infection on pregnancy outcome.

## Evaluation of Infants Born to Mothers Infected with WNV During Pregnancy

When an infant is born to a mother who was known or suspected to have WNV infection during pregnancy, clinical evaluation is recommended. Further evaluation should be considered if any clinical abnormality is identified or if laboratory testing indicates that an infant might have congenital WNV infection.

## Prevention of WNV Infection During Pregnancy

Pregnant women should apply insect repellent, containing DEET, to clothes when exposed to mosquitoes and wear clothing that will help protect against mosquito bites. Spray insect repellent on

clothing in order to minimize direct skin contact. Apply insect sprays or lotions to skin sparingly. In addition, whenever possible, pregnant women should avoid being outdoors during peak mosquito-feeding times (i.e., usually dawn and dusk). Precautionary measures for mosquito abatement should be taken by emptying all standing water in and around property.

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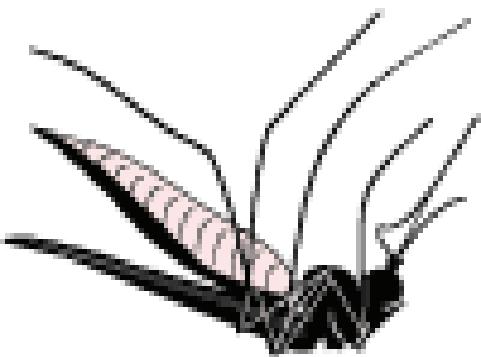
Should you have any questions or need further information about testing or interpretation of test results regarding WNV, please contact:

Utah Department of Health  
Health Resource Line  
1-888-222-2542  
[www.health.utah.gov/wnv/](http://www.health.utah.gov/wnv/)  
Bureau of Epidemiology  
1-801-538-6191

Pregnancy RiskLine  
1-800-822-BABY (2229)



- West Nile Virus is expected to hit Utah this summer.
- We estimate more than 41,000 women will be pregnant during the peak season (July-September).
- The risk to a pregnant woman and her fetus are not well defined, but may be of concern.
- See inside (page 3) for details regarding clinical information and guidelines for testing.



## West Nile Virus Information About Important

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